

# INTRODUCTION

The health of most American children has improved remarkably over the past two decades. Low-birth-weight or otherwise vulnerable newborns who remain in the hospital long after birth have benefited from increasingly sophisticated technology. The technology, often requiring extended hospital care, has an unwanted side effect of subjecting these infants to abnormal environmental conditions, including separation from parents. The opportunity for close parent-infant contact is limited, and parents may have problems relating to the child in a home environment.

Resources within the community have not been developed, or if present, are not organized to encourage early discharge and to assist the family in aiding their child. Those newborns with their disabilities and continuing needs are dramatic examples of a more pervasive problem. Of the unmet health care needs of American children, the needs of children with handicaps are those most deeply felt.

To promote an understanding of these needs and to develop strategies to meet them, Dr. Koop convened the second Surgeon General's Workshop at The Children's Hospital of Philadelphia, December 12-14, 1982. The Workshop on Children With Handicaps and Their Families brought together health professionals, financing experts, consumer representatives, patients and families, and local, State, and Federal Government officials for analysis and discussion of the subject.

The major objectives were twofold: (1) to examine the problem of services delivery to handicapped children and their families in order to develop strategies for providing community-based services as an alternative to acute care facilities; and (2) to examine current funding mechanisms for providing services in order to develop new strategies of improving financing for safe, appropriate, and cost-effective health care for these children and their families in nonacute care facilities.

The Workshop focused on four basic goals:

- To strengthen the families' ability to cope;
- To promote adequate support services on a community basis;
- To organize and coordinate existing community resources on a regionalized theme; and
- To identify and remove legislative, financial, and other barriers.

Following the keynote address and the presentation of model programs for care of the ventilator-dependent child, the participants were assigned to small Work Groups. Their duties were to:

- Plan an organizational approach to health care for ventilator-dependent children and their families;
- Promote family and patient autonomy for care in home or community environments;
- Develop strategies for organizing and providing this care in a cost-effective manner;
- Recommend monitoring processes for quality assurance and funding dynamics;
- Draw implications for nationwide care for all children with handicaps;
- Suggest areas for continuing study.

Because of the complexities involved in attempting to cover all handicaps, the Work Groups concentrated on the severe, specific problems of the ventilator-dependent child as a prototype for discussion. These findings were extrapolated for all handicapped children.

The participants reconvened in plenary session to present their findings and to develop a synthesis of their recommendations. Workshop Chairman Robert G. Ketrick, M.D. conceptualized the deliberations in a summation to the Surgeon General, who accepted and commented on them. This report is designed to disseminate the conclusions of the Workshop to the widest possible audience.

## WELCOMING ADDRESS

Ginny Thornburgh, Advocate for the Handicapped

We are proud to welcome you from across the nation to Pennsylvania and to Philadelphia. We are particularly proud to welcome the Surgeon General back to Children's Hospital. There's no place like home.

I'm not here because I'm the wife of our governor. I'm here because I'm a mother. I'm the mother of Peter Thornburgh, who is a superbly handsome, superbly fine young man who happens to be mentally retarded. Peter would have been institutionalized had he not had superb medical care, very fine community services, and a willing family. I think that represents the kind of family we're going to be talking about here. The goal of this Workshop is to devise public and private methods for handicapped children to live as independently as possible.

We are very, very proud in Pennsylvania to have responded to the needs of ventilator-dependent children. Two years ago, I visited the unit here in Children's Hospital where I met a number of ventilator-dependent children and their moms and dads and brothers-in-law and uncles. All of these children wanted to be home. Among the children I met was my friend, Jill Eshelman, who is here today. Jill is a ninth-grader in public school in Pennsylvania and now lives at home with her mom. That's possible in Pennsylvania, and it's going to be possible in your State also, I hope. But the ventilator-dependent children are only the tip of the iceberg. Solving that problem alone won't solve the problems of handicapped children.

There are going to be three things that are necessary, in my opinion, to allow handicapped children to live as independently as possible.

First of all, we've got to get physicians and health planners to be willing to respond in a creative way—not just the old tried and safe ways but in ways that are new and exciting and right.

Number two, the advocates. That's what I call myself. Do you remember in reading about Socrates the word gadfly? I love that word, and I consider myself a gadfly on the system. Advocates today have to be politically realistic. Solutions to the problems of the 80s are not going to happen just because they are right or just or compassionate. They also have to be sound fiscally. The advocates of today have to be smart politically and seek their goals in a sound political way.

Number three, the general citizenry, the people of the nation. The people have to be willing to become educated. There is a lot to learn about disease and health and syndromes and medical care. The citizenry has to be willing to learn, and you and I have to approach them on their level. If we don't elevate the educational level of the citizenry, the legislators are not going to vote the funds for us to get our programs through.

The parents, too, have to be willing to take a risk. I know that. I've done it with my son, time and time again. Risky decisions were made, and I was willing to say "yes." Two years ago, I was willing to say "yes" when he moved out from under my wing to a group home in the community. Try that when you're a mom or dad and when you know what the system's like. It's tough. But it's working. Peter Thornburgh, so that you'll know how fine he is, is a very dependable person. He now rides the public bus, transfers, rides another bus. He now cooks scrambled eggs for himself, turning on the burner. You know, I never would have let him turn on the burner at home. And last night, he called his best girl in Pittsburgh and asked her if she bought a new dress for the Inaugural Ball. So thanks to good policy and thanks to a community that was available when we needed them, Peter Thornburgh is an independent man.

You have a task that is not pie in the sky. No more of that. We need a blue-print for action, something Dr. Koop can present to the Nation to allow disabled children to become as independent as they can.

## EXCERPT FROM KEYNOTE ADDRESS

C. Everett Koop, M.D.

Surgeon General and Deputy Assistant Secretary for Health

Our task at this Workshop is not an easy one. We are asking each other to deal with very complex issues as we keep in mind the many levels of complexity: the *emotional* and the *moral*, the *medical* and the *technological*, the *social*, the *psychological*, and the *financial*.

Of course, we won't be explicitly attending to each of these levels always. But we know they are there. When we talk about "cost-effective life-support systems," we are implicitly putting some dollar value on a human life. We may not want to admit it, but that's certainly one outcome. So the moral and the technological and the economic do come together, whether or not we feel comfortable about it.

There is yet another complication. The lives we are concerned with at this Workshop are new lives. We are able to interact with them, but there is a clear limit to this interaction. We know, for example, that there can be no true "informed consent" with a newborn. So we must turn to the parents of those new lives and assume a joint responsibility through their understanding and consent.

I think it is essential for the attending physician, in particular, to sit down with the family and carefully go through the nature of the infant's condition, what the medical experience with such a condition has been so far, what kinds of options are open for immediate action, and what kinds of options may be open to the family and the physician later on.

It would be a mistake for me to dwell entirely on the potential hurdles and barriers to the care of disabled infants and children. The overwhelming direction of infant and child health in this country is toward improved care and better outcomes.

The infant mortality rate is still declining: the provisional rate for the 12 months ending in July, the latest figure we have, stands at 11.3 infant deaths per 1,000 live births, the lowest 12-month rate in our history. There had been some feeling in the past year or so that we were hitting a plateau, that the curve would begin to flatten out and we would have to begin dealing with the hard-core issues affecting perinatal care in this country. But the curve is *not* flattening out. It is still going down at about the same angle and we have not yet hit any infant mortality rate that is, for our society, the irreducible minimum.

Of equal significance is that most of the infant lives we are saving are *healthy* lives. There is no real evidence so far that the infant *morbidity* rate goes up as the infant *mortality* rate goes down. But, in all candor, we have not done the kind of research that's required in order to elevate this conclusion above the level of what it really is: our best instinctive, visceral response to the data.

Of course, we don't need statistical curves that go sharply up or down to understand the impact a disabled infant has upon the parents and upon the attending medical and social services staffs. Giving birth is a highly complex emotional, psychological, and physical event, even when a healthy baby is delivered. How much more complex it can be when the infant is disabled. All the persons involved—the family and the hospital staff—they all share the feelings of guilt and inadequacy.

But medicine and social service cannot take the place of the family. Rather, the professionals should use their talents and expertise to help the family survive and function, to renew its strength and foster its cohesion. For it will be the family that will provide the long-term help required by the disabled infant. The family's daily decisions, routines, and relationships will translate into the support, the therapy, the special education, the recreational efforts, and all the other aspects of the best possible quality of life for the disabled child.

The overwhelming number of parents of handicapped newborns—over 95 percent—take responsibility for their children, take them home, and try to absorb them into their family life. Our challenge is to help those parents understand, love, and care for their child.

As I indicated earlier, even if they do get the best possible guidance, disabled infants and their families may still face a future of enormous human challenges in their communities and in their own homes. How much more difficult their lives will be, then, if the initial help they receive from the hospital staff is not the very best that's available. Staff excellence, therefore, must form the basis of all our procedures, routines, and work plans.

### **Consensus of Principles**

A good staff is open to the needs of its patients and draws liberally from the strengths of its own members. A good staff operates on a consensus of principles that form the basis for the way we care for our disabled patients and their families, and, I believe these few principles do have a strong though unspoken power among us.

The first principle is to *obtain open, direct, and personal communications with the parents of a disabled child.*

When an infant is born with Down syndrome, spina bifida, some congenital defect, a damaged organ system, a missing or deformed limb, or one of any number of disabling conditions, the physician-patient relationship is no longer casual. It cannot be flip. And it won't be short-term. The physician has to translate the complicated medical terminology into words the parents can understand—and not fear.

There are ways to train medical staff—physicians of *all* ages, I might add—to settle down to a close, compassionate, highly personal, and possibly prolonged relationship with parents who may be setting out on a long and intricate journey in human growth. Young physicians especially need this kind of training. They will have just come from an educational system that measures success almost exclusively in terms of curing and repairing patients and returning them to a normal state. But many disabled neonates cannot be “cured” or readily “repaired.” They may never approach what might be considered a “normal” state of functioning at any time in their lives—and their lives may be very brief.

A second principle practiced by an excellent staff is this: *the staff must recognize and understand the natural responses of parents to their disabled baby . . . their feelings of sadness, guilt, anger, even of shame.* Parents' questions may come in a rush, but the answers must be given only after a great deal of careful thought. The staff now represents not only medical care—but the outside world as well. In such intense human situations, a staff has many assignments and few choices. No matter how serious the infant's condition, it is essential that staff members not transmit in any way a sense of hopelessness or futility, or in effect, go into mourning for a child who is still very much alive, however severe the physical or mental burden.

We are outraged at parents who physically abandon their children . . . and I am outraged at physicians who intellectually abandon their patients. No matter how sophisticated our diagnostic technology, it can *still be wrong*. By the same token, the survival power of the human being—even in the tiny newborn state—can be truly awesome. We need to transmit this understanding to parents, even as they verbalize their most troubling thoughts.

But I have a particular *caveat* to raise here. I want to emphasize that restraining oneself from speaking in terms of hopelessness is *not the same thing as offering false hopes* to confused and frightened parents. We need to be cautious, honest, and objective with parents. And we need to build on their strengths.

At this time we do not have a clear idea of the number of mothers who take home infants born with single or multiple disabilities . . . who try to absorb the information about the care they need . . . or who try to cope with all the attendant problems—but who ultimately decide to surrender their children for adoption or institutionalization.

It has been my experience that many of these decisions to give up a child were made by parents who would have been rewarded a hundredfold if they had not given them up but instead had held on for just a little longer and had been given just a little additional support. The child, in the overwhelming number of such cases, would also have had a chance at a more fulfilled and fulfilling life.

The third principle emphasizes the *full participation of the parents and siblings in all the processes of medical care*. In as many ways as possible, a staff needs to demonstrate to the parents that they are needed as partners. It is not artificial, not some ruse to trick them into doing something they ought not to do. Quite the reverse. There is no substitute for loving, caring parents.

As soon as possible, the physician and other staff members should try to get the child literally into the hands of the family. A parent staring through a pane of glass at a little baby in a covered isolette over in the corner is not my idea of "family togetherness." Even though the baby may be bandaged, intubated, monitored, and fed with a hyper-alimentation line, the parents can and should touch, and . . . if possible . . . hold and cuddle the child.

As a last principle I would say that the medical and social service staffs need to *play a positive, active role in linking up the child and the family with available social and medical support groups in the community*.

In other contexts and for more routine situations we all advocate *continuity of care* and *total care* for our patients and clients. How much more important is this kind of approach for infants with disabilities? The medical

and social service staffs who take this principle seriously have the set of mind and the firm professional commitment to become advocates for their patients and the parents. In that role, they help make the vital connections between home and community resources.

People who work in hospitals, clinics, schools, or other service institutions are usually familiar with most of the community services network—and very often they assume that everyone else has the same information. But, in point of fact, most people do not.

Most people may, on occasion, have used one or another social service or health agency or may have regularly contributed to certain voluntary organizations concerned with a particular disease or disability. But when people are faced with the immediate need to get information, apply for help, request certain resources, make connections, make decisions—much of their past experience and knowledge becomes somehow disjunctive.

If the parents and the staff have formed a relationship based upon the principles I've talked about this morning—even if they have already made a firm commitment to give their child all the care and love needed—they may still be totally overwhelmed by the byzantine complexity of our social service delivery system. Society may seem to be conspiring against their humanity.

I think it's important to remember that "social services" as such are not exclusively the province of the "social service worker." Certainly we expect a greater professionalism from a person trained in this field, but there are many other disciplines within the hospital community that can be helpful, too. I am thinking in particular of that new and extraordinary breed of individual known as the "neonatal intensive care nurse." They bring to their job a total commitment to child health and welfare . . . not in the abstract, but in the real world of day-to-day care for tiny vulnerable lives.

When we introduce the patient's family to the world of social services, we can help make good things come to pass, but we cannot *insure* that good things will come to pass. Families have rich and varied biographies. Fortunes rise and fall. Children do or do not all get along with each other. Mothers may or may not succeed in developing a strong bond with their disabled infants. Husbands and wives may or may not cleave to each other till death does them part. And the disabled infant . . . growing child . . . young adult . . . and adult are part of that evolution, that miracle of human growth. And, like all miracles, you cannot predict how this one will turn out.

That word—"miracle"—is being worked very hard these days. It tends to be used with every new development in medical technology, regardless of the outcomes. Certainly there may be much that seems to be "miraculous" about infant intensive care technology, but the outcomes are also mixed.

### **A New Category of Disability**

I mentioned that the infant mortality rate is coming down and that, as near as we could tell, most of the babies we are saving are healthy babies. But the picture is really not that simple. A number of the infants we are saving are premature or arrive with a low birth weight or are immature in some aspect of their development and exhibit respiratory distress. They may be taken immediately to an infant intensive care unit, or transported to one,

and put on a respirator. These babies are usually the ones that might not have survived their birth just a few years ago. Today they are alive. But they represent a new category of disabled child—a category *created* by technology. The alternative for such babies had once been death.

The cost is very high, not only in dollars but in family stress as well. The child is denied the initial, vital attention of that mother. Opportunities for early bonding are gone. The entry of that child into the family is delayed . . . and, depending upon the circumstances, possibly delayed forever.

I know others on the program today and tomorrow are going to speak more particularly to this example. But I want to underscore its significance:

*First*, the respirator-dependent child is a creature of our new technology and, in fact, needs additional technology to relieve the state of dependency. This is no longer a unique problem for medicine. It is very useful, therefore, to take a close look at the problem of the respirator-dependent child in order to search out those concepts and approaches that may produce workable solutions in other, similar situations. The way we handle this particular problem may, in fact, be a kind of model for the way we might deal with many other disabilities that tax our human and material resources.

*Second*, the problem of the respirator-dependent child concerns technology . . . but not exclusively. Fundamental to the handling of this problem, I believe, are the several principles promoting staff-family interplay. This is where technology leaves off and basic humanity takes over.

*Third*, it provides us with a rather clear assessment of how adequate—or inadequate—our social services may be, not just for patient care but for total family care as well.

And, *fourth*, it is possible for us to begin some longitudinal studies of how these patients do, both in the hospital setting and in the home, what the costs are at each place, what the effects are of changes in technology, what the cost/price history is, and so on.

Such an opportunity rarely appears in which all these four elements are present. So I am delighted to see you here, looking hard at the overall problem of providing better care for disabled children and their families, and also focusing in on the specific example—or “model”—of the care for the respirator-dependent child and the family.

Again, let me thank each one of you for coming today, for contributing your time, knowledge, and experience—and your basic humanity—to this problem. In the long run, I think that the way we deal with problems like this reveals just what kind of a society we are.



# **PRESENTATIONS OF PROGRAMS FOR CARE OF VENTILATOR-DEPENDENT CHILDREN**

## **THE PENNSYLVANIA PROGRAM**

Robert G. Kettrick, M.D.

Over the past decade we in the medical community have made tremendous technological progress in preserving the lives of the newborn. This audience, representing the health care industry, is largely responsible for providing the medical environment that enables these children to live, although sometimes with disabilities and possible handicaps. This imperfect solution is of no less importance for the legislators, administrators, and executives present than for the doctors and nurses. You also represent our society and our system of values. These disabled children are the children of our society and in that sense they are your children.

Today, in the United States, there are legitimate health care alternatives that are not available to these children and their families. You, as members of society and as contributors to the health care effort, need to insure that all reasonable alternatives of care are available.

With respect to the case model of the ventilator-dependent child, my message to you is simply this:

1. In many instances we can take better care of children and adults outside of an acute-care facility. This better care can be provided in the home at less cost than that which institutional care seems to mandate.
2. In order to provide this other legitimate alternative—home care—we need to identify and correct those circumstances which prevent its implementation.

Let me start to develop these points by sharing some of our experiences. Consider the child who has a total thoracic ectopia cordis. From a clinical standpoint, these children would not have survived. At least they never did before, but now three of these children are alive. Two are still dependent on mechanical ventilation. The first of these children remained in our hospital for just over three years with hospital charges exceeding \$750,000. He then went home on mechanical ventilation, supplemental oxygen, and with a tracheostomy. During the succeeding two years at home he was eventually decannulated. During that time he commuted to a community special education program, and part-time nursing service was supplied through New Jersey's Supplemental Social Security Income/Disabled Children's Program. These were devastating times for this family, who had to struggle to provide care, work, and pursue further education.

Consider another type of patient—the premature infant. Ten years ago the infant of less than 1500 grams was likely to die. Six years ago my daughter, a 1300 gram preemie, spent one month in a neonatal intensive care unit, one week in a transitional unit, and was sent home at 1900 grams. The times have changed; more and more premature infants weighing less than a thousand grams at birth are living. Some, however, live to develop bronchopulmonary dysplasia and in many cases chronic respiratory failure secondary to that bronchopulmonary dysplasia.

Still another category of patient is represented by Chris, a child with a post-infectious demyelinating syndrome which left him ventilator-dependent. The family was educated in the techniques necessary to provide care at home and the child was discharged. Part-time nursing was provided through union insurance. At that time he had a portable, battery-operated ventilator, battery-operated suction, and a portable liquid oxygen unit. The community made resources available to take him to school and to provide for his education.

When I talk about care at home as an alternative, I am talking about the routine use of advanced life support technology in the home, in a very real sense transplanting elements of the expensive intensive care environment to the home. Can it be done? Absolutely! Can it provide better health care for the child? Absolutely! As long as you select your patients and family properly, and as long as you can find a way to pay for it.

#### **Etiology of Ventilator-Dependency**

Ventilator-dependent children fall into three categories. First, there are those with severe bronchopulmonary dysplasia, often with right ventricular hypertrophy. Originally, we accepted these patients from infant intensive care units all over the Delaware Valley. More recently, we have had to restrict our transfers to those from our own infant intensive care unit. Their mean duration of hospitalization is 499 days, and the range is between 285 and 1,250 days.

The second group are those children with neuromuscular disease. The children with severe infant botulism are particularly satisfying to work with. They all get better, but it may take 3 to 6 months to wean them from mechanical ventilatory support. These are children with severe motor impairment whose cognitive potential generally is not affected. Eventually, all of these children have their care transferred to a home environment. However, effecting that transfer is time-consuming as evidenced by their own mean duration of hospitalization—214 days.

The third group of children consists of those with congenital anomalies directly associated with chronic respiratory failure and those anomalies whose management was associated with complications producing chronic respiratory failure; e.g. esophageal stenosis, tricuspid atresia, and pulmonary atresia. For this group, corrective surgical procedures, growth, and development usually allow eventual independence from mechanical ventilatory support. The mean duration of hospitalization for this group is 198 days.

Because of limitations of skill and knowledge inherent to our “state-of-the-art” medical and surgical expertise, results are often supportive rather

than curative. We have achieved a patient population which would not have survived before the regionalization of medical services; part of the achievement comes from efforts at the local care facility to stabilize and to transport the infant to tertiary care facilities. The intensive care environment, with its technological sophistication, its surveillance by nurses and physicians, and its rapid responsiveness to patients' needs contributes to chronicity. Both public and private financial support have underwritten this medical effort and therefore have contributed to the survival of patients with chronic respiratory failure.

### **Disposition**

There are a number of possible disposition alternatives for the child requiring long-term ventilatory support. First, the intensive care unit. It is expensive—approximately \$250,000 per year. It forces separation from the family. It exposes the child repeatedly to stressed personnel, stressed families, and gallows humor along with catastrophic deaths, bloody intervention, and group assault. It is a terrible place to grow up, but grow up these children do. Currently 9 of the 28 beds in our acute care facility are occupied by children with chronic respiratory failure. There have been times when 16 of our 28 intensive care beds were occupied by such children.

Yet, the chronic care facility or extended care facility for ventilator-dependent children doesn't exist. Why? Ventilator-dependent children are a relatively new problem, and many people don't want to believe the problem exists. Many see death as a more cost-effective alternative; many see death as a more humane alternative. Many are scared by the economics and the experience with dialysis. However, the reality is that this patient population does exist and will continue to exist. Extended care facilities may have to be developed.

The acute care hospital intermediate unit is an essential step towards successful implementation of home care. The pediatric intensive care intermediate unit of The Children's Hospital of Philadelphia has evolved into a community where ventilator-dependent children come to live while we begin to sort out their medical and social needs. The unit has adapted a plan for the support and protection of the ventilator-dependent infant. It recognizes that:

1. The responsibility of the medical community is to provide an environment that will support and protect the child from those phenomena that will adversely affect organ, system, child, and family growth and development.
2. The natural history of each of the diseases which produce chronic respiratory failure largely dictates the rapidity and/or possibility of wean.
3. The child belongs to the family. Medical paternalism is actively discouraged. We have a goal of an integrated family with a strong parental sense of responsibility for the care of their child.

The environment for these children is very important. Efforts are directed towards providing a warm, humane, and stimulating environment. Non-invasive technology and treatment are stressed. For example, respiratory

status is assessed using impedance pneumograph, capnograph, transcutaneous oxygen analysis, and clinical presentation. Blood studies are drawn primarily to provide support for presumptive diagnoses, not for routine screening. Drugs are administered enterally. Intramuscular injections are avoided since they are painful, and their cumulative effects have been associated with muscle fibrosis and limitation of motion.

We try to provide a normal rhythm to the day. After the lights are turned on in the morning, there is a pattern of bathing, tracheostomy care, dressing, feeding, and so forth. Lights are dimmed for naps and consultants are encouraged not to disturb these naps. Parents can be with the child at any time, and other family members are encouraged to visit and interact with the child. The hospital is home for these children, and the environment should reflect such an atmosphere as much as possible.

The transfer of an infant to a unit for chronic ventilatory support can produce significant stress for the family. The caregivers whom the family have grown to know and trust are left behind. An uncomfortable realization that there is to be no cure is reinforced emphatically by the other children and their technologic chains. There are concerns about finances. Helping the parents through this period and eventually developing a strong alliance with them is part of our goal. Our efforts are directed towards: 1) a mutual trust established through clear communication, consistency, honesty, and provision of a non-threatening environment; 2) incorporation of the family into the care plan. Short- and long-term goals are reviewed, explained, discussed, and adjusted to meet the needs of the parents; 3) establishing the parents as effective, confident caregivers and advocates of their child; 4) when appropriate, transfer of the child's care to a home environment.

Parent-infant bonding is essential. What we often see are parents who are afraid to touch or hold their child. We intervene and set the example by touching the child, stroking the child, and encouraging them to do so. We appreciate that the parents have gone through the first stage of bonding when they feel comfortable enough to go to the crib, drop the side, and independently gain access to the child. Then we move on to encouraging those aspects of care which represent caretaking: providing clothes, activity of daily living, caretaking tasks, comforting, and meeting special health needs.

We then encourage and reinforce the parents' identifying the child as their own and as their responsibility. This process might be called desensitization, or bonding, or behavior modification. It might also be looked at simply as education with interim goals and the need to meet certain criteria before moving from one level of education to another. Indeed, these families do move through basic child care, sensory motor stimulation, nutritional care, daily respiratory care, and equipment management.

Invariably, the parents reach a point where they feel that they are just as capable of taking care of their child as the doctors and nurses. While they were evolving to that point, they saw other children go home with supplemental oxygen or tracheostomy, or mechanical ventilation. They see children and families coming and going for out-patient visits and sometimes just for socializing. Eventually their sense of self-confidence and peer pressure brings them to ask the question, "Can we take our child home?" The answer is, "That's a substantial commitment—let's sit down together and

review it and see if it's the best thing to do.' We do that, and invariably for the parent who asked this question, it is the best thing to do.

We examine various aspects to determine whether it's appropriate for the child to go home. Inability to wean is considered. This might just as well be inability to be independent, or hyperalimentation, or inability to be independent of intravenous antibiotics, or inability to be independent of dialysis. We look for patient stability. We look for an involved family unit. We look for an appropriate home environment. In our experience, this environment might be on the main line, a trailer park, a farm, or an apartment. Generally, the physical plant that is appropriate for the family is acceptable for the ventilator-dependent child. An important consideration relates to the electric capacity which must be adequate so that the ventilator and suction will work if someone decides to use the toaster. We look for two skilled caregivers. For this we use a checklist with some 30 different points of skill and knowledge that the family needs. We look to see if service and supplies are readily available in their community. These needs have not been problem areas in Pennsylvania or New Jersey. Finally we look for money.

### **Financing Home Care**

Consider the family who has a major medical coverage with INA, Aetna, or Prudential. The policy rarely pays for extended nursing care in the home. However, we can call them and explain that the child has respiratory failure which requires hospitalization. In addition, we point out that the child's family has major medical coverage so that the annual cash flow is substantial. We then outline to the company how they can reduce their annual cash flow by about 75 percent. Happily, we have not been disappointed. In all cases they have elected to capitalize the equipment needs for home care and to underwrite nursing for these children.

We had another child who was insured with the Carpenter's Union. His benefits did not extend to home care. We explained this to the regional representatives who referred us to the board of directors. We sat before the board of directors and explained the child's needs and the cash flow problems. The board of directors felt that they could not make an exception for any one child, so they voted to change the policy and make it retroactive so that this particular child and all others could be covered.

Contrast that with this response that I received from a Health Maintenance Organization when I asked for financial help to underwrite home care. "The child is already through our \$100,000 corridor and now she is covered by our re-insurance carrier. We wouldn't dare send her home and risk having her re-admitted. If we did that, we would have to pick up the corridor again. Keep her in the hospital. It's paid for." The question of what was best for the child wasn't to be discussed, but we did discuss it further with the involved parties and were eventually able to effect a solution which allowed for underwriting of home care.

The response from Blue Cross is variable. In Pennsylvania, the important precedents have been set and currently they will pay for the equipment and partial nursing support.

CHAMPUS has evolved, and an important precedent has been set. Recall the child with the total thoracic ectopic cordis. More recently, an Air Force dependent was discharged home with mechanical ventilation. All equip-

ment, including backup equipment, was funded through CHAMPUS, as was sufficient nursing to allow parents respite and the opportunity to keep their jobs. It wasn't easy for the parents—they worked alternating shifts—but they did have their son home with them after 3 years of hospitalization. Within 4 months the child was weaned, and 3 months thereafter he was decannulated.

Until recently we couldn't budge the medical assistance system. They would pay hospital costs, often up to \$210,000–220,000 a year per patient, but they would not provide nursing support for care at home. However, important precedents are now being set. Secretary of Health and Human Services Richard Schweiker has set up a Federal review board so that these cases can receive individual review and he recently allowed for waiver of rules so that Medicaid money can be used for at-home care. Just four weeks ago, Governor Kean of New Jersey came to The Children's Hospital of Philadelphia to send off the first such patient to New Jersey.

Several years ago, the Commonwealth of Pennsylvania, through the leadership of Representative Mary Ann Arty, and Governor and Mrs. Thornburgh, made monies available for a pilot program for home care of ventilator-dependent children. The program provides for disbursement of Commonwealth of Pennsylvania Department of Health and Welfare funds to meet the legislative intent of Appropriation Act 17A of 1980. Through the terms of this Act the Commonwealth contracted with a private corporation to develop a program to allocate State funds for services, equipment, and supplies for care at home of ventilator-dependent children. This public-private experiment has been cost-effective, has facilitated hospital discharge for ventilator-dependent children, and has increased the availability of community support services.

The program now supports 25 children and their families in their homes. However, there are over 200 more patients in acute care environments in Pennsylvania who might benefit from this kind of program—with enormous savings to the third-party payment system.

Providing home care for ventilator-dependent children does not necessarily require more dollars. Indeed, we can extend our resources by defining less expensive and equally effective alternatives to hospital care and by redesigning the reimbursement process to meet patient needs to allow for payment of the less expensive alternatives. In the model problem of the ventilator-dependent child, care can be better at home. There are clearly fewer infections, development progresses more rapidly, and where weaning is possible, it occurs more rapidly. In addition, care is less costly for this group at home.

Our system of health care delivery has effected a growth in the numbers of disabled infants, children, and adults. Among these disabled, ventilator-dependent children have been denied access to reasonable alternatives of care because of misperceptions about the complexities of their needs and because the system has not adjusted to meet the needs of that which it has produced.

Our experience in Pennsylvania indicates that care at home in particular is a reasonable alternative for ventilator-dependent children. This alternative has not been available to all families who might benefit from it. We need to learn how to make it uniformly available and of high quality.

## THE NEW YORK EXPERIENCE

Mathew H. M. Lee, M.D.

Goldwater Memorial Hospital is a 912-bed facility specializing in long-term rehabilitation and treatment of chronic illness. As part of the Health and Hospitals Corporation of the City of New York, the hospital maintains a longstanding affiliation with New York University Medical Center. The long-term rehabilitation effort focuses on the team approach to patient care along with the individual's discharge potential; that is, discharge of each patient as a viable, productive, and self-supporting member of society, living outside of the institution in the general community.

We have recently conducted a study to explore the independent living problems of the severely handicapped respiratory patient as related to his personal adjustment, health care, and economic survival.\* The objectives of the study were as follows:

1. To assess medical and social resources available to the severely disabled respiratory patient living independently in the community.
2. To evaluate the cost effectiveness of these resources.
3. To develop a comprehensive rehabilitation service plan which includes medical treatment, public health nursing, pulmonary testing on a routine basis, and maintenance of life-support equipment and motorized wheelchairs.
4. To assess the need for other types of clinical care including occupational therapy, physical therapy, speech and audiology, psychological therapy, and vocational counseling.
5. To assess vocational potentials and training of these patients as a function of their medical condition and functional mobility.

The following table demonstrates that home care of the ventilator-dependent child should be thought of as a continuing process which can proceed into adulthood. One-third of the patients studied have lived at home for more than 10 years.

*YEARS LIVING IN COMMUNITY AFTER  
ONSET/DIAGNOSIS*

	<u>N</u>	<u>%</u>
Less than 2 years	7	8.1
2 - 5 years	30	34.9
5 - 10 years	19	22.1
10 - 15 years	10	11.6
Greater than 15 years	18	20.9
N/A	<u>2</u>	<u>2.4</u>
	86	100.0

The next table shows distribution of the vital capacities of the patients in our survey.

*PERCENT VITAL CAPACITY*

	<i>N</i>	<i>%</i>
0 - 10%	12	14.0
10 - 20%	18	20.9
20 - 30%	14	16.3
30 - 40%	10	11.6
40 - 50%	9	10.5
Over 50%	22	26.7
	85	100.0

You will note that some people in the study (34.9%) have vital capacities reduced below 20% of their normal predicted volumes, and that a total of 63 people (73.2%) were below 50% of their predicted vital capacity. In past years, people with this degree of pulmonary compromise died from carbon dioxide retention and subsequent cardiopulmonary arrest, usually precipitated by pneumonia or other respiratory infections.

The twenty-two (26.7%) patients falling into the over 50% vital capacity category may not experience respiratory distress under usual circumstances. However, during a cold or intercurrent infection, they require ventilatory support to exercise their lungs and help mobilize secretions. Often they cannot expel thick secretions and require medical treatment with antibiotics and expectorants, along with judicious physical therapy of the chest (pulmonary toilet) during an illness. All of these clients are at risk when faced with a respiratory infection and require prompt and experienced medical intervention.

Ideally, professional rehabilitation services allow the patient to move toward independence at his own rate. In this ideal, support and guidance are fostered, while the individual encounters and overcomes the problems of a new lifestyle. This support can be diminished progressively as the individual reassumes the ability to make a choice and carry out his needs. However, there is a definite existential difference between these elements of human potential and actual access to knowledgeable medical care and supportive services. These services are the *sine qua non* for conditions favorable to community life and subsequent employment.

During the course of this study, lengthy discussions with patients strongly suggested that they do not want to exhaust the financial supports offered by society. These individuals do not consciously choose physical immobility and dependency. They desire to regain control of their own lives. Urban planners and health planners alike are aware of the existence of disabled people, and gains have been made in many areas. Patients acknowledge reforms, yet the fact remains that the day-to-day experiences of living in a wheelchair are still frustrating. Simple survival in a world not ready to receive quadriplegics is a continuing struggle.

In this regard, we at Goldwater Memorial Hospital are planning to meet the medical health maintenance needs of patients by establishing an Independent Living Center. Goldwater Memorial Hospital's specialized and unique respiratory care services are available currently to hospital inpatients and a large number of community-based residents. The Center will assist the patient in maintaining his community residence by the provision of individually selected service support.

Observation of the lifestyles of members of the severely handicapped community serve to expand our conception of human potential. Comprehensive rehabilitation efforts, along with re-education, allow us to recast an image of an immobile, dependent human being, to that of an active, autonomous, reflective being, despite severe physical and functional limitations. Medical and health practitioners must give increased attention to implementing the consistent support needed to help the patient achieve this goal. When appropriate support is available, the patient has the capacity and the need to assume responsibility for his own existence. In many cases medical and institutional expenses have been reduced following the comprehensive rehabilitation and educational training of motivated patients. The cost effective nature of rehabilitation is not to be underestimated.

\*This study was supported by a grant from the New York State Office of Vocational Rehabilitation. Copies of the report of this study can be obtained by contacting our hospital.



## II

Patient H. S.—Age at discharge—1 year

Discharge Date: 6/1/81

Condition: Totally ventilator-dependent

- ventilator at night
- diaphragmatic pacers during day
- no oxygen required

*Hospital vs. Home Care Costs  
6 Month Cost Comparison  
Private Insurance—Midwest*

<i>Hospital Costs 1981</i>	<i>Home Care Costs 1981</i>	
\$189,250/182 days	\$45,630/184 days	Total
\$ 1,040	\$ 250	per day
\$ 31,540	\$ 7,610	per month
	76% Decrease	

Secondly, our program has demonstrated recognizable values in having these children grow up in a more normal and human environment. Their personalities broaden; they interact with their parents and siblings; they attend school; and they can participate in their religion. Some improve to the point of no longer requiring support.

By 1980, it had become apparent that the application of advanced medical knowledge and sophisticated technology by organized teams of health care professionals was saving an ever-enlarging number of disable children needing a variety of solutions and services not readily available. Demonstration projects of home care were not enough. Some children needed other options for social, educational, and future vocational reasons. Study led to the calling of a Conference on the Chicago Program, in October, 1981, to understand better and to define the present situation and to plan for the future. At the Conference, we asked, "Whatever Happened to the Polio Patients?"<sup>1</sup>

Why polio? There are three reasons:

- First, the modern medical disciplines of critical care and rehabilitation medicine have evolved from the organizational and technological advances made in response to the worldwide crisis created by polio.
- Second, the resulting excellent health care has created a new and enlarging population of survivors of many diseases and conditions who depend upon life-supportive technology.
- Finally, these new survivors face many problems and have a diversity of unmet needs similar to those of the polio patient of the 1950s.

What is the situation *now* regarding the ventilator-dependent child?

<sup>1</sup> The proceedings of the Conference are available from the Rehabilitation Institute of Chicago, Dr. Don Olson, Director, Education and Training, Northwestern University Medical School, Rehabilitation Institute of Chicago, 345 E. Superior St., Chicago, IL 60611. Tel: (312) 649-6179 or Eli Henig, Rehabilitation Institute of Chicago. Tel: (312) 649-6190.

### **The Health-Care Perspective**

*Regional acute care centers* utilize valuable technological and professional resources for months and even years at an enormous cost. Facing decreased Federal, State, and insurance cost-reimbursement, they must limit their facilities' capacity to serve acute care patients.

*Regional rehabilitation and long-term care institutions* have available or adaptable resources to meet many of the needs of these children on ventilators. They could provide cost-effective, appropriate care if they had adequate preparation to do so. At present, these institutions do *not* accept these children. Such institutions also face economic constraints and need new directions for their missions.

### **The Consumer Perspective**

The needs of a ventilator-dependent child disrupt family unity and tax all the strengths of a marriage. Both *health care consumer* (patient and family) and the *physician in the community* face inappropriate utilization of institutional resources because of a lack of information, education, and/or an organizational approach. Consumers have the potential to help find the solutions to these problems if given the opportunity. Instead, the excessive costs of acute-care domiciling are indirectly added to everyone's burden as taxes and insurance premium costs.

### **The Organizational Perspective**

*Health Care Service Providers* are finding an increased demand for their services and products, but mechanisms for reimbursement do not meet the diversity of services they can provide and the cash-flow they require for operation. They seek guidelines for meeting a standard of care and mechanisms of coordination and communication with health care facilities, third-party payment agencies, and insurance companies.

*Public and Private Funding Sources* recognize that alternatives to institutionalization can save money on a case-by-case basis. There is some uncertainty about the *total* cost-savings once a more workable and universal system of reimbursement is in place. In some cases, fragmented funding for human services can be combined for a *total* cost-savings. Funding sources recognize that there presently exists no standard of home care, no operating procedure, and no established case management/case monitoring system. Furthermore, there is concern about the appropriateness of treatment by medical providers. For example, the Blue Cross Association has recently enacted "Medical Necessity Programs," such as one for Respiratory Care, which is a responsible, well-planned approach to reduce unnecessary costs for non-essential services.

*Voluntary Service Organization and Non-Profit Health Care Agencies* have excessive demands upon limited resources. They need education and information to adapt to meeting new needs and guidelines to determine services.

*Other Organizational Possibilities:* Many organizations that care about people (religious service organizations, and community-based voluntary groups such as Rotary, Lions, Kiwanis, Elks, and Shriners) have “grass-root” resources. Many search for new directions. They can help provide local support for intact families or alternatives to the family. Today excessive health care costs have nearly exceeded our ability to pay. Unless we design operational systems and reimbursement mechanisms, we face the danger of curtailment of services and a resultant decline in the quality of life, or even survival, for some disabled people. Our past demonstrations and those of others abroad have proven that a higher quality of care can be more appropriately given with the family or in the community at enormous cost-saving. We can provide better care for less money. The solution of the problems of the ventilator-dependent child will have far reaching and universal benefits because of appropriate application to the many other complex health care and societal problems we face today.

## II. Home Health Care—Case Management Approach

Eugene E. Bilotti, Administrator/SSI-Disabled Children's Program

Years of singular growth and development had left health programming and social service agencies where it was hard to conceive of a plan that would place a severely medically involved youngster in his or her own home with \$16,000 worth of sophisticated medical equipment and around-the-clock nursing services. Nevertheless, this is what the ventilator-dependent children brought to the scene. The Illinois Department of Public Aid had no official policy concerning such children. With each involvement, it had to establish an exceptional policy waiver. The Federal government was beginning to address the issue by a task force established to study and subsequently to make recommendations for the care of these children. Exceptions were also required by Crippled Children's programs as well as insurance carriers.

The need for such a plan was obvious to all concerned parties. The most notable was that *the child would be placed in the loving environment of his or her own home. A second was that there would be an immediate cost reduction of approximately two-thirds of the cost for institutional care.* The limitations of such programs were also obvious in the medical/safety and social areas. When planning for these children to go into their own homes, we needed to be aware that emergency medical support would be absent. Obviously, careful detailed planning was necessary in order to not threaten the child's life and/or safety. All the assets and liabilities being weighed, it was decided that we would attempt to place a child in his own home. We developed a case management approach. It should also be noted that *other children with similar needs, although perhaps not ventilator-dependent, would need to follow the same type of case management approach.*

The following is the Illinois approach to home placement:

**1. Medical Plan**

Our Illinois approach begins with a very thorough medical protocol. This plan is detailed to the point of specifying every piece of equipment and a careful list of supplies. It also indicates who is to order the equipment, the designation of the primary physician, provisions for backup emergency care, a designated hospital to assume emergency responsibilities within the geographic area, an available respiratory therapist to monitor the program, and a careful description of other professionals needed.

**2. Case Management Plan**

A home case management plan is developed that clearly details and limits the persons and agencies involved.

**3. Nursing Services Plan**

This plan includes a program for procuring the nurses, a plan for training and for determining an hourly rate of reimbursement. The nursing plan also details a projection aimed at reducing the number of nursing service hours from 24 to 16 hours a day and then to 8 hours a day, with the hope that the family will eventually be able to function without regular nursing service.

**4. Financial Planning**

An exact financial plan is essential. Without a means of paying for the total program, all programming would abruptly end. The role of involved and legally responsible insurance carriers is determined. A plan is developed with the medical assistance unit of the Department of Public Aid defining their role and the amount of responsibility they will assume. The plan also includes a projection to reduce costs within six months to a year.

**5. Family/Home Care Plan**

The suitability of the family situation needs exploration. It is generally anticipated that a professional social worker will be needed at this point, for the family needs to understand the likely impact of this placement. The physical arrangements of the home need evaluation. There should be a suitable room for the child with proper heat, light, space, and an alternate power source.

**6. Community Involvement Plan**

The overall plan details the involvement of the community. The local fire department, police department, and highway department need to be aware of the presence of a ventilator-dependent child. Arrangements also are made for local emergency medical services such as a local doctor, preferably a pediatrician, to tend to this child in emergency situations.

**7. Equipment Plan**

An equipment list includes such items as backup suppliers, local pharmacy suppliers or providers, and ready information dealing with service or repair of the equipment. It is anticipated that backup equipment will be on hand.

**8. Discharge Plan**

There is a detailed discharge plan that includes emergency alternative plans, such as the local hospital that would tend to the child in an emergency and a contingency plan for return to the hospital from which the child was discharged.

Although we feel that overall case management system in Illinois is not in its final form, we do feel that we have made strides in systematizing our approach and in getting these children safely and successfully into their own homes.

### III. The Consortium

Arthur Kohrman, M.D.

The needs of the child with long-term dependence on high technology for continuing care must be met at several levels. The most effective means of providing services will be the bringing together of the various institutions and services within a given region. We are forming such a consortium in the Greater Chicago area with the support of the funding agencies of the State of Illinois, particularly the Division of Services for Crippled Children and the Department of Public Aid.

Our initial efforts are focused on children with long-term or permanent needs for mechanical ventilation. We have begun a network of services and care which will ensure continuity, quality, and the greatest hope of the appropriate placement. It is anticipated that regional tertiary acute-care hospitals will continue to receive patients needing meticulous attention to airway, pulmonary, and cardiovascular care. It is hoped that a large percentage of children with long-term or permanent ventilatory care needs will ultimately be placed in home settings. Some can be discharged directly home from acute care units, but most will require intermediate-level facilities while caretakers in the alternative setting can be trained. For many, poverty and unstable homes make it impossible to construct adequate settings at home. We hope to train foster parents and set up new "families" for these children.

An institutional consortium approach is now being organized consisting of Children's Memorial Hospital (the largest children's hospital in the region), Wyler Children's Hospital (the acute care hospital of the University of Chicago, Department of Pediatrics), Michael Reese Hospital (also University of Chicago, Department of Pediatrics) and LaRabida Children's